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and Their Families; A Case Controlled Study

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INTRODUCTION

The first objective of this work is to evaluate the social, emotional, and behavioral quality of life (QOL) of children with NF and explore potential linkages between NF and QOL in these 3 domains. The second objective of this work is to evaluate parental distress, family functioning, and child rearing practices. It is hypothesized that the social and emotional status of children with NF plays an important role in predicting eventual functioning and the quality of life they obtain. To determine which medical and psychological variables are involved, a cross sectional study of peer relationships, emotional well-being, and family functioning is required. Peer relations play a central role in children's social and emotional development and are fundamental for the development of adequate social skills and for the emergence of a healthy self-concept. Although a growing body of empirical evidence has shown peer perceptions of social competence are predictive both of current adjustment and of future adaptations during adolescence and through adulthood, no data are available on the peer relationships of children with NF. Additionally, while several psychometrically sound measures of emotional well being are available, these have not been reported for children with NF. Finally, we could locate no studies focusing on parent distress, family functioning, or child rearing concerns. A high incidence of learning disabilities, ADHD, and behavioral problems have been reported for children with NF. Clinically, parents often voice concerns that their children have few friends, are immature, and are teased because of their appearance or clumsiness.

BODY

No tasks were accomplished during this reporting period.
We were not able to obtain HSRRB approval to collect data.

KEY RESEARCH ACCOMPLISHMENTS:

None. We were not able to obtain HSRRB approval to collect data so the employment of all trained staff on the award was terminated. All protocols were approved by the local Institutional Review Boards in Cincinnati and Houston.

REPORTABLE OUTCOMES: Staff were trained and then laid off.

CONCLUSIONS: The institutional review boards at Children's Hospital Medical Center and MD Anderson both reviewed the protocol favorably. The HSRRB has not approved this research protocol. We cannot obtain HSRRB approval for this protocol.

REFERENCES: None

APPENDICES: None

PERSONNEL RECEIVING PAY FOR THIS RESEARCH EFFORT:

CHMC
None

MD Anderson
None